



**NKDEP**

National Kidney Disease  
Education Program

## **NKDEP Patient/At-Risk Work Group Conference Call**

November 27, 2001

### **MINUTES**

#### **Present:**

Tom Hostetter, Mimi Lising, Phyllis Payne, Susie Warner, Purnima Chawla, John Bower, Phyllis Ermann, Ann Compton, Carolyn Mosley, Kris Robinson, Linda Holomah, Dori Schatell

#### **Could not attend:**

Wendy Brown, Mary Clark, Janice Lea, John Flack

#### **I. Introductions**

Each work group member on the call stated their name and affiliation.

#### **II. Purpose of Patient/At-Risk Work Group**

Mimi Lising advised the group that this would be an ad-hoc work group as opposed to a standing work group. The focus of the program during this phase will be on targeting African Americans at risk for or undiagnosed with CKD and Primary Care Providers. Mimi also stated that we are looking to the group for advice, resources and suggestions on the development of activities and materials and implementing and disseminating them.

#### **III. NKDEP Current Activities**

##### *Compendium*

Phyllis Payne reported that we are gathering information on existing education materials and programs for patients and professionals on CKD, not ESRD. The compendium will consist of the following sections: on-line resources; educational programs; patient educational materials; professional educational materials; and a list of other organizations with information on CKD. We will make the compendium available on our website and possibly create a publication.

##### *Website*

Mimi Lising reported that the website will contain downloadable materials and it will be launched in mid-December. The website will contain links to our Partners, archived meeting reports, calendar of kidney related events, materials

and a place where partners, steering committee members, patients and clinicians can go for information.

#### *Pilot Site locations*

Pilot sites will provide us with an opportunity to try out some strategies to determine what works best, the ultimate outcomes is to conduct a national campaign based upon the findings of the pilot sites. In addition, the intent is to create awareness of CKD among at-risk African Americans and Primary Care Physicians. The pilot sites were determined by high-density of African Americans, and local interest or infrastructure.

Tom Hostetter reported that we will have four pilot site locations:

Baltimore/Washington, Atlanta, Jackson, MS and the just decided, Cleveland, OH. Dr. John Bower advised that Dr. Herman Taylor (Director of the Jackson Heart Study) is very interested in working with the NKDEP. Kris Robinson stated that this population is very hard to reach since they do not consider themselves kidney patients. Linda Holomah advised that we should focus on improving African Americans dietary and food preparation habits.

#### *Focus Groups*

Mimi stated to the work group that the objective of the focus groups is to obtain information about the audiences knowledge, perceptions and practices about kidney disease in order to develop campaign messages and materials.

Purnima Chawla stated that the focus groups will inform the activities of the pilot sites. We will be seeking focus group participants based on the following criteria: diabetes or hypertension; middle aged people (40-50's who are at risk for kidney disease) except in hypertension where the age criteria will be younger for African American males. Dori Schatell suggested that we seek people in the early 30's for the focus groups. John Bower said that we should also make obesity a criteria since it is a major problem and a risk factor. Phyllis Ermann suggested that their African American outreach efforts in churches in Baltimore and in Atlanta may be an avenue to recruit people as well. There existed a consensus among the work group participants that the NKDEP should use family history as a criteria for focus group participation and several participants suggested dialysis clinics as an avenue for recruitment.

Purnima suggested to the group that we will have separate focus groups at each of the four sites. She will also look at barriers, access to health care, environmental support areas, etc. We will also follow up on diet in the focus groups. There will be 9 people in each focus group for a total of 36 individuals. Linda Holomah also suggested that Black family reunions would be a good outreach and dissemination channel.

#### *Other NKDEP Work Groups (Treatment and Evaluation)*

Tom Hostetter reported that two other work groups are intact. The first is the Treatment Work Group that consists of nephrologists and primary care providers whose goal will be to have consistent targets and produce simple guidelines for

diagnosis and treatment. The second work group is the Evaluation Work Group that consists of Bill McClellan and Dan Stryer, AHRQ and they met via conference call on November 21<sup>st</sup>. Tom reported that Purnima Chawla is putting together a standard evaluation plan that is flexible enough to allow for variation among the pilot sites. The evaluation will include process measures (materials distributed, partner satisfaction), and outcome measures (change in awareness and behavior among health care providers and people at risk). Purnima suggested that we take advantage of any opportunities to add our questions onto existing surveys such as the Jackson Heart Study.

#### **IV. Current Activities of Work Group Members in CKD or African American Outreach**

Ann Compton reported that they are working with the Arthur Ashe Center to conduct a “Hypertension Awareness Day” for blood pressure screening as well as the NKF to do KEEP screenings. They also conduct pre-ESRD education sessions for patients and families.

Carolyn Mosley reported that Chi Eta Phi’s signature cause is hypertension and its outcomes. In October, they do hypertension activities to raise awareness and provide education. They target about 100,000 individuals per year. They partner with the American Cancer Society (ACS) and the American Diabetes Association (ADA).

Tom Hostetter provided an update on the NKF K/DOQI launch in early 2002 and the KEEP program in Wendy Brown’s absence. NKF has enlisted Alonzo Mourning as its spokesperson for a public awareness campaign.

Kris Robinson said that in 2002, AAKP will hold 20 CKD seminars through out the nation for people at risk. They also have an AAKP Patient Plan booklet and will be adding a book and newsletter specifically geared towards CKD. They will also be unveiling a CKD section on their website soon that includes an internet newsletter on CKD. They are also developing a CKD educational package.

Phylis Ermann stated the AKF has a booklet on CKD that goes out to the colleges. They also have a toll-free helpline number. Additionally, they have a specific African American Outreach program, with 3 facets, whereby they exhibit at Black Expo for Sisters Only, Black Family Reunions and Church Fairs. They distribute 3 CKD brochures at their expos and do blood pressure and blood glucose screenings.

Linda Holomah is available to help in any way she can and can add her perspective as a person with CKD.

Dori Schatell reported that the Life Options Rehabilitation Program will launch a CKD website in January. They have an interactive web-based education program called Kidney School, with 16 modules ([www.kidneyschool.org](http://www.kidneyschool.org)) for people with CKD and early dialysis patients. They have a relationship with Oxford Health Plans to collect research data on the self-management practices and activities of CKD patients and preliminary results indicate that African Americans are more involved in self-management activities than other populations. Their research has

shown that patients with higher levels of kidney knowledge had higher scores on functioning and well-being.

John Bower is involved in the KEEP program that has received a huge response. The Jackson Heart Study will follow 6,500 patients for the next 20-25 years.

V. Administration Issues

Next conference call

Mimi advised the group that we would like to hold monthly conference calls (about 1 hour in length). Susie Warner will canvas the group for availability for the conference calls.

Work Group Meeting in 2002

We would like to hold a face to face meeting in Washington, DC in early 2002. Susie Warner will canvas the group for availability for a 1 day meeting to discuss strategic planning in January/February.

Suggestions for other work group members

Mimi advised the group that we are trying to get the National Congress on Black Churches and ISHIB as members of the work group. It was suggested that we add social workers and Dori and Linda knew of a few social workers who would be interested in participating in the work group.

The call adjourned at 1:15pm EST.